

Delaware Developmental Disabilities Council 2007 Position on Health Care

Position Statement

All people of Delaware must be able to access health care and health-related services, including oral health care and eye care. Treatment must encompass the whole person with dignity. Emphasis must be placed on self-determination, access, affordability, quality, and accountability. Health care and health-related services should include:

- Personal choice and autonomy supported by Physician expertise.
- Increased awareness among people with disabilities of the steps they can take to develop and maintain healthy lifestyles.
- Early evidence-based screening/diagnosis/treatment for disabilities.
- Extreme caution in the prescription and use of psychoactive and psychotropic medications and informed consent must precede the use of such medications.
- Increased knowledge among health care professionals and provision of tools to screen, diagnose, and treat the whole person with a disability with dignity. This includes times of emergency management and recovery.
- Full access to disease prevention and health promotion services.
- Physical access to medical environments including all equipment and machinery that may be needed to complete a thorough examination and assessment.
- Access to health clubs in the community.
- A comprehensive array of health, rehabilitation, personal, and support services.
- Affordability, portability and continuity of coverage to and from group, individual and government plans.
- Equity in coverage between mental health and physical health benefits. At all times, treatment should be voluntary with an informed choice on the part of the beneficiary. Parity should not make it easier to force people into accepting “treatments” they do not want.
- Medicaid Waivers that support people appropriately, no matter their disability.
- Studies and/or surveys should occur with direct input from people with disabilities concerning health care and health-related service needs, access, and quality.
- The inclusion of people with disabilities on hospital boards and others.
- An independent, impartial review board that includes people with disabilities to review problems as they arise.
- An appeals process when disagreements exist.

Discussion

The Delaware Developmental Disabilities Council supports the full inclusion of people with disabilities in all facets of community life; this includes the choice to be healthy. The Council believes that it is the responsibility of all Delaware citizens to improve the quality of life for everyone who lives here by promoting health and well-being.

It is accepted that people who take advantage of preventive care and maintain healthy lifestyles are less costly to the health care system and the government than people who are not afforded the opportunity to do so.

According to the U.S. Surgeon General, “Today, 54 million Americans, or one in five people, are living with at least one disability, and most Americans will experience a

disability some time during the course of their lives.” People with disabilities are more likely to experience secondary diagnosis as a result of their disability.

Reported in the 2006 “Health Risks of Adults with Disabilities in the State of Delaware: A Retrospective Analysis of Data from the Behavioral Risk Factor Surveillance System” (This list is not all inclusive.):

- 16.4% of the adult population has one or more physical, mental or emotional problems that limit their activities and 5.7% need to use special equipment as a result of one or more health problems.
- Approximately 20% of adults with disabilities are unable to work as a result of their physical, mental or emotional health problems.
- Adults with disabilities have significantly less income than those adults without disabilities.
- In general, adults with disabilities have reported that they have fair to poor health.
- The percentage of those with disabilities unable to see a doctor because of cost is substantially higher than the percentage of the adult population who do not experience some form of disability.
- Adults with disabilities are more likely to have had a heart attack or stroke than adults without disabilities.
- Cigarette smoking is higher among adults with disabilities than adults without disabilities.
- Adults with disabilities are more likely to have had a checkup in the past year than adults without disabilities.

The Commission on Community-Based Alternatives for Persons with Disabilities (H.R.#90, 2002-2003) published its findings in “A Call to Action: Building a Community-Based Plan for Delaware”. This Call to Action includes Health Care as an area of significant need for Delaware and reports that “major gaps in services in Delaware exist in medical care, dental care, and attendant services.”

Considering all of this information, the Developmental Disabilities Council believes it is past the time for equity in our health care and health-related service system.

Recommendations

Delaware must:

- 1) Establish a fair and equitable health care and health-related service system that will allow full access to that same system.
- 2) Develop a coordinated system in which people with disabilities will be able to receive general health care and dental services ongoing or as needed.
- 3) Develop and coordinate an educational requirement of all physicians, dentists, and health-related clinicians and professionals who practice in the State of Delaware on disability.
- 4) Develop and coordinate an educational option and/or opportunity for people with disabilities on disease prevention and health maintenance.
- 5) Provide accountability of services of health care in Delaware on behalf of consumers of that same system.
- 6) Increase incentives that would create a larger health care work force; such as, increased wages that reflects cost of living increases, benefits that support workers and families, increased educational opportunities for workers to enhance the quality of their work.

- 7) Develop a back-up/emergency system for the State's personal attendant service program.
- 8) Develop a State and local emergency operations plan that includes the needs of people with disabilities of all ages to ensure the safety and well-being of these same people in times of emergency management and recovery.
- 9) An independent, impartial review board that includes people with disabilities to review problems pertaining to health care as they arise. Members should participate with vigor.